

Michigan Department of Health and Human Services

Newborn Screening News

Fall 2020

The Michigan Department of Health and Human Services (MDHHS) Newborn Screening Follow-up Program works together with the State Newborn Screening Laboratory and coordinating centers to find and treat infants who need early medical care.



NBS Quarterly Reports and Stellar Performance

During the second quarter of 2020, six hospitals met all seven of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Bronson Methodist Hospital
- Henry Ford Allegiance Health
- Henry Ford Wyandotte Hospital SCN

- McLaren Thumb Region
- Munson Healthcare Cadillac
- St Joseph Mercy Ann Arbor

Performance Goals for NBS Quarterly Reports

- 1. Less than 2 percent of screens are collected >36 hours after birth
- 2. Greater than 90 percent of screens arrive in the state laboratory by the appropriate day
- 3. Less than 1 percent of screens are unsatisfactory
- 4. Greater than 95 percent of electronic birth certificates have the NBS card number recorded
- 5. Greater than 90 percent of specimens have a returned BioTrust for Health consent form that is completed appropriately
- 6. Greater than 90 percent of newborns with a dried blood spot have pulse oximetry screening results reported

We encourage you to use the information in the quarterly reports to improve your part of the NBS system. If you have any questions, please call the NBS Follow-up Program at 517-335-4181.

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Newborn Screening Card Fee Change:

On October 1, 2020, the cost for the initial newborn screening card increased to \$137.10 (from \$135.29). The cost for the repeat (pink) cards changed to \$124.34 (from \$122.60). The fee supports the Newborn Screening Laboratory, Follow-up, and Coordinating Centers. The fee is adjusted annually to reflect changes in the Detroit Consumer Price Index and to cover the cost of adding new disorders to the newborn screening panel.

The Detroit Consumer Price Index increased 0.5% this year. To reflect this change, MDHHS applied a \$0.68 increase to the cost of each initial (blue) newborn screening card and a \$0.61 increase to the cost of each repeat (pink) card purchased. An additional fee of \$1.13 was included to support screening for spinal muscular atrophy (SMA). Screening for SMA began in March 2020.

If you have questions regarding the fee, please contact the Newborn Screening Follow-up Program at newbornscreening@michigan.gov.

NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: newbornscreening@michigan.gov



2020 Virtual Newborn Screening Conference

The Newborn Screening Program hosted three virtual newborn screening conferences for hospital staff this fall. The trainings covered a variety of topics including: developing a newborn screening hospital protocol, a history of newborn screening and where we are today, critical congenital heart disease family experience, and more!

A total of 77 attendees, representing 45 birth hospital across Michigan, participated in these conferences. Please email newbornscreening@michigan.gov if you'd like a copy of the presentations given at the conferences.



Infant Safe Sleep Resources

Did you know the MDHHS Infant Safe Sleep Program offers a wide variety of free educational resources? The MDHHS Infant Safe Sleep website, www.Michigan.gov/SafeSleep has resources for parents and professionals including videos, handouts, online trainings, recorded webinars and other supplemental materials.

MDHHS provides resources on a variety of topics, such as the sleep environment, infant development and protective factors:

Infant Safe Sleep
Baby Eating and Sleeping: What is Normal?
Breastfeeding & Safe Sleep
Is this Infant Safe Sleep? Checklist
Soothing a Crying Baby
Swaddling
Don't Let Baby Get Too Warm
Smoking & Safe Sleep

How to Help Families Practice Infant Safe Sleep

The MDHHS is pleased to announce the release of three new infant safe sleep resources. These were created in partnership with the Greater Detroit Area Health Council.

Baby, We've Got Your Back Brochure
Baby, We've Got Your Back Poster (8.5" x 11" size)
Baby, We've Got Your Back Brochure for Grandparents

options on the Safe Sleep website under <u>Information for Professionals</u>.

You can order most of the resource materials for free from the MDHHS Clearinghouse, www.healthymichigan.com/. If you want to learn more about infant safe sleep, there are a variety of training

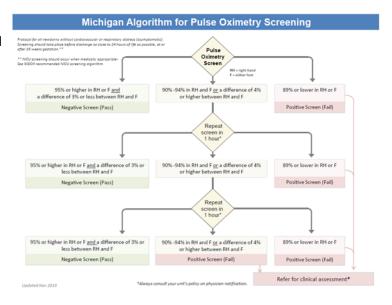
There is a <u>list of local safe sleep resources</u>, such as cribs or training sessions, for families on the website. To receive email updates on training opportunities and new resources, sign up for the <u>Infant Safe Sleep for Professionals email list</u>. You can also contact the MDHHS Infant Safe Sleep Program at <u>MDHHS-InfantSafeSleep@michigan.gov</u> for additional assistance.

Critical Congenital Heart Disease Algorithm Changes: Not So Fast!

A recent article in the American Academy of Pediatrics (AAP) suggested updated strategies for pulse oximetry screening for critical congenital heart disease (CCHD). The article discusses findings from an expert panel that met in September of 2018 suggesting that there is sufficient evidence to recommend modifying the current AAP

recommended algorithm by 1) requiring an oxygen saturation of at least 95 percent in both (formerly either) the upper and lower extremities to pass and 2) requiring only one repeat screen instead of two for cases that neither pass nor fail initially.

Effective April 1, 2014, the MDHHS implemented statewide screening of all Michigan newborns for critical congenital heart disease using pulse oximetry prior to hospital discharge. The Newborn Screening Program and the CCHD Advisory Committee requires that newborns be screened prior to hospital discharge, as close to 24 hours of age as possible, using the approved MDHHS CCHD screening algorithm. The MDHHS CCHD screening algorithm follows the original guidance, and currently recommended algorithm, from the AAP,



requiring that a newborn have saturation of at least 95% in either the upper and lower extremities to pass and 2 repeat screens for cases that neither pass nor fail initially.

The Newborn Screening Program will closely monitor whether or not the AAP will officially endorse the recommended algorithm changes suggested in the article and take the appropriate steps involved in changing the algorithm should Michigan's CCHD Advisory Committee recommend adopting the modifications for our MDHHS CCHD screening algorithm.

Please wait for official guidance from the Newborn Screening Program prior to making changes to your internal processes. Changing your algorithm now could result in low performance on your quarterly reports. If you have any questions, please contact Kristen Thompson, Newborn Screening Program Coordinator at thompsonk23@michigan.gov.



Virtual Hospital Visits

Lois Turbett, NBS nurse consultant, had planned to visit hospitals every three years to discuss their newborn screening process. She is currently unable to visit hospitals in-person because of the COVID-19 response but has been successful in visiting many hospitals online via Microsoft Teams. Prior to the actual visit, Lois Turbett contacts the NBS coordinator through a series of emails to gather information about the hospital's NBS process and to provide hospital-specific information on unsatisfactory specimens, cards that had errors, and a detailed specimen transit report. For more information about scheduling a NBS virtual hospital visit, email Turbettl@michigan.gov or call 517-335-1966.

2018 NBS Annual Report Summary

Every year, the Newborn Screening (NBS) Program releases an annual report that provides detailed information about the previous birth year. These reports are available on the NBS Program website (www.michigan.gov/newbornscreening) and contain information on updates that occurred during that birth year, the number of babies screened overall and the number identified with disorders on the NBS panel, performance metrics for each disorder including detection rate, false positive rate, and positive predictive value, and quality assurance information including the performance measures on the quarterly reports and time to treatment by disorder.

In 2018, a total of 108,277 infants were screened in Michigan and 253 (0.2%) were diagnosed with a disease on the blood spot panel. Overall, one infant out of 428 screened was diagnosed with one of the disorders. Since the NBS Program began in 1965, more than 6,800 Michigan newborns have been identified with disorders on the NBS blood spot panel. Congenital hypothyroidism and sickle cell disease are the most commonly identified disorders, affecting 101 and 60 infants born in 2018, respectively. The third most commonly diagnosed disorder is cystic fibrosis, with 21 cases diagnosed in 2018. In addition to



disorders included on the panel, more than 2,700 carriers were detected in 2018.

Upcoming Holiday Courier Schedule

Lower Peninsula Hospitals:

Wed, November 11 – holiday/Sunday schedule
Thurs, November 26 – holiday/Sunday schedule
Fri, November 27 – holiday/Sunday schedule
Thurs, December 24 – No Pickup
Fri, December 25 – holiday/Sunday schedule
Thurs, December 31 – No Pickup
Friday, January 1, 2021 – To be determined
Monday, January 18, 2021 – holiday/Sunday schedule

Upper Peninsula Hospitals:

Thurs, November 26 – no UPS pickup
Fri, November 27 – **UPS will pick up**Thurs, December 24 – **UPS will pick up**Fri, December 25 – no UPS pickup
Thurs, December 31 – **UPS will pick up**Friday, January 1, 2021 – no UPS pickup

TECHNICAL ASSISTANCE

Lois Turbett, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. She can be reached by email at turbettl@michigan.gov to answer your questions. Kristen Thompson, NBS Coordinator, is also available to work with hospitals on CCHD pulse oximetry screening and reporting and can be reached at thompsonk23@michigan.gov. Together we can achieve our goal that all children diagnosed through newborn screening receive prompt and careful treatment in order to live the healthiest lives possible.

Please remember to share the quarterly newsletter with staff!

If you have questions please contact the NBS Follow-up Program at 517-335-4181 or newbornscreening@michigan.gov or visit our website at www.Michigan.gov/NewbornScreening